



Original Article

School inclusion challenges in Tunisian children affected with Cerebral Palsy.

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Abstract

Background

Cerebral palsy (CP) is one of the most frequent pediatric neurological affections. Related psychomotor disorder usually lead to difficult social integration. The aim of this study was to assess different educational difficulties in Tunisian children with cerebral palsy.

Methods

A cross-sectional study was performed including children with CP and their parents. Sociodemographic, cultural and clinical characteristics were collected using pre-established form. School outcomes were measured using quality-of-life scale (CPQOL) in its Arabic language version validated for caregivers.

Results

Sixty-one children were included (33 boys and 28 girls). Mean age was 8 years (6-14). School registration rate was 31%. The enrolment was in mainstream school in 80% of the cases. The Quality of students life assessed using the score was objectively altered in 80.8% of cases. Most of the studied cases were feeling non-competitive.

Conclusions

Few educational outcomes associated with cerebral palsy were precepted in our study. These findings might be due not only to limited communicative and intellectual ability but also to variable CP children environmental factors.

Key words

Cerebral palsy; School inclusion; Communication; Function; Outcome.

Introduction

Cerebral palsy (CP) is the main cause of pediatric motor disability. It consists of disorders of movement and/or posture, permanent, not progressive caused by different lesions occurring on developing or immature brain before the first two years of life. Motor disorders maybe associated with cognitive, communicational and behavioral abnormalities [1].

The schooling process and educational pathway of these children remain poorly codified in Tunisia. These patients are rarely totally managed in special needs centres. Few are included in the regular educational system with considerable rate of school leavers [2].

The aim was to perform a comprehensive assessment of challenging school inclusion of CP Tunisian children.

Material and Methods

I- Study design

This cross-sectional study was conducted over four months in our physical medicine department (Sahloul university hospital Sousse ,Tunisia). Cooperating children without comprehension difficulties were included. Study exclusion criteria were:

- Age< 6 years old.
- Non-consenting parents.
- Comprehension difficulties.
- multiple disabilities.

Precalculated sample size of fifty-six was used based on estimated expected school inclusion rate of 12% (precision (i) =5% ; risk (α) = 5%).

II- Data collection

Based on data from medical records, we determined the clinical forms and socio-economic conditions of the included cases. For children with CP not attending school, we focused on the causes. For the others, educational difficulties were determined through a quality-of-life questionnaire(CP QoL scale).

This scale was a self-administered questionnaire for the primary caregiver. It is composed of several questions exploring 5 domains (D):

D1= Social well-being and acceptance.

D2= Emotional wellbeing and self esteem

D3= Access to services

D4= Pain and impact of disability

D5= Family health

Each question includes a satisfaction scale according to a Likert scale from 0 "not satisfied" to 9 "very happy (appendix).

III- Definition of variables

We considered the child satisfied for response greater than 5 for each domain's item. The average satisfaction rate was calculated for school related items. Each statement in the questionnaire was given a score ranging from 1 to 9. All item scores were converted to 0-100 score according to the scoring rules detailed the CP QOL Questionnaire User Manual. Final average score was calculated for each domain.

IV- Data analysis

Data entry and analysis were carried out by SPSS 26.0 software. The quantitative variables were described with means ± their and deviations- standard. Qualitative variables were summarized with absolute and relative frequencies.

V- Ethical considerations

Approval from the Ethics Committee of the "Ibn El Jazzar" Faculty of medicine ,Sousse, Tunisia. Anonymity and personal privacy were respected for data collection. Written consent was obtained from all the enrolled children parents or legal tutors.

Results

Our specimen included 61 children, 33 boys and 28 girls. Sex ratio was 1.18. Mean age was 8.56 years (6-14) (table 1). Among the 61 children included, 19 (31,1 %) were registered in a school.

Non-enrollment of CP children was due to distant or absent school in twenty-nine cases (47.5%). Parental decision of non-inclusion was motivated by predicted failure and frequent absenteeism in 7 cases (11.4%).

Table1 : Population characteristics.

		n(%)
Gender	M	33(54.1)
	F	28(45.9)
Age(mean±SD)		8.56(2.7)
Father's age		43.1(4.6)
Mother's age		39.7(4.62)
Parent's educational level	Illiterate	31(51)
	Secondary school	22(36)
	High school	8(13.1)
origin	Rural	39(62.5)
	Urban	22(36)
Health insurance	Yes	31(51)
	No	30(49)
Clinical form	Diplegia	21(34)
	Hemiplegia	26(42.6)
	Quadriplegia	14(22.9)
Regular follow up	Yes	14(23)
	No	47(77)

Among the nineteen scholarized case, the percentage of normal educational mainstream schools integration is 78.9% (n=15). None of these cases has received physical assistance inside the school. Five children (26,3 %) had adapted priority of examination time. Regarding the quality of CP cases life, the overall satisfaction rate was 55.1 (±16.5). The "Emotional well-being and self-esteem" domain was had highest score of 58.9 (±19.9). Regarding the domain "participation and physical health" CP children were less satisfied. The score results by domain items were variable. Highest scores were noted for "relationship with teachers" (5.47±1.54), "relationship with peers" (5.74 ±1.52) and for the item related to the Ability to interact with peers (5.58 ±1.74). Lowest scores were noted for "the acceptance of peers" (5.26 ±1.79), "ability to participate in school" (5.05 ±1.51), and for "physical activity"(4.32 ±1.80). these results are detailed in (figure 1).

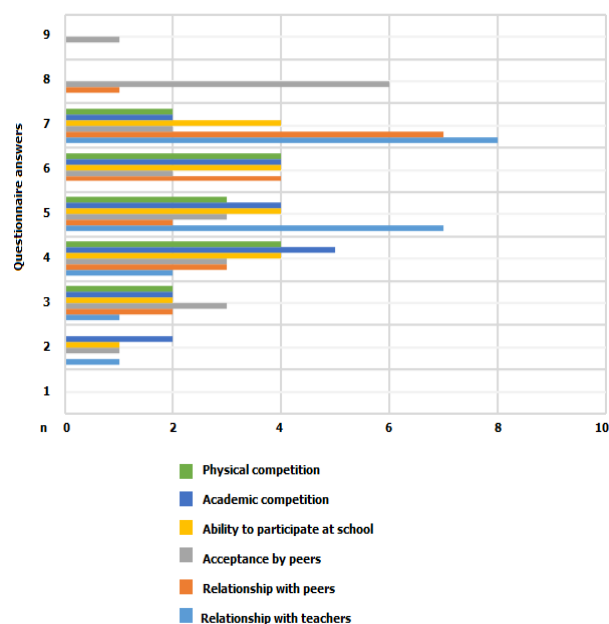


Figure 1:CP QoL scores

Discussion

Education of children with cerebral palsy was exhaustively implemented and managed in special needs centers for decades. The objective was to deliver one-to-one patient-centered educational and health assistance to improve the communicational, cognitive and behavioral associated disorders [3]. Several studies have examined schooling model impact on the educational outcomes of children with cerebral palsy. Findings have shown worse educational outcomes than typically developing children specially in centred educational systems [4-7]. Universal declaration of human rights about equal education rights, regardless of physical or social special needs motivated the insertion of children and adolescents with cerebral palsy in mainstream schools model [8-10]. However, these children are still facing several inequalities due to multiple interfering familial and social related factors [11]. Effective schooling pathway for children with disabilities remains poorly defined in Tunisia. The aim of our study was to investigate whether CP children have lower school achievement and if school achievement varies by specific factors. We focused also on the assessment of the quality of life of CP children enrolled in the mainstream system. Western and African studies previously conducted in the same topic were essentially focused on of the physical and communicational reduced capabilities as leading factor to achievement depletion and difficult school integration [12-15]. However, there was no objective assessment of the educational facilities specialized material and human resources was done. The integration of children with cerebral palsy requires adapted structures and staff to ensure best school outcome [16]. Cerebral palsy may affect not only children's physical but also indirectly the intellectual capacities. The educational level of the parents, the availability of nearby specialized facilities and family resources may affect the integration and increase the rate of school leaving [17]. Family economic, cultural and social resources may impact the capital available for these children to face the challenging schooling step [18,19]. In Tunisia, resources are differently distributed in families, and these differences have an impact on how and when the parents invest in their children. Our analysis revealed that children of highly educated parents obtain higher scores than children who had parents with a short education. This is valuable in both disability and normal capacity situations. Confrontation of CP children marks with normal children marks in mainstream school students showed no significant difference. Difficult school inclusion are more likely to be related to the conditions of the preschool age cerebral palsy management. These insufficiencies, once added to multiple others socioeconomic and cultural factors, may make schooling of these young patients extremely challenging.

This study had preliminary scale for the assessment quality of life (QoL) of children with cerebral palsy. Overall QoL is generally poor in children with disabilities. This condition may also affect QoL of healthy siblings [20,21]. The Limits of our study at this point were multiple specially the short size of children cohort that didn't enable the correlation of QoL scale items with the daily school life variable domains.

Several consistent studies recommended the development of personalized patient-centered QoL assessment for CP children and adolescents. This scale may include, in a supportive physical environment and adequate equipment, the assessment of the acceptance of the disability, emotional well-being and self-esteem and personal perception of human relationship [22-25].

Conclusions

Inclusive schooling is fundamental in children education. This implies that all children learn together in mainstream schools regardless of any special educational need. In Tunisia, children with cerebral palsy are still suffering from poor schooling outcome mainly because of extra-scholar financial, organizational and cultural issues. Inclusion in mainstream education system Had objectively improved the outcome compared to results of special need centers. However, these findings must be confirmed on larger scale studies.

Conflict of interest: None

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